

Self-management of Type 2 diabetes:

Processes for setting up a diabetes and prediabetes support intervention in socioeconomically disadvantaged communities in Sweden

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**SELF-MANAGEMENT OF TYPE 2 DIABETES:
PROCESSES FOR SETTING UP A DIABETES AND PRE-DIABETES SUPPORT
INTERVENTION IN SOCIOECONOMICALLY DISADVANTAGED
COMMUNITIES IN SWEDEN**

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Self-management of Type 2 diabetes: Processes for setting up a diabetes and pre-diabetes support intervention in socioeconomicallydisadvantaged communities in Sweden

THESIS FOR DOCTORAL DEGREE (Ph.D.)

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This thesis is dedicated to my family, my rock home and away!

To my beloved uncle Agweru Opila Abraham (1950- 2006) – Rest in peace!

ABSTRACT

Background: Type 2 diabetes and pre-diabetes are major public health challenges, disproportionately affecting disadvantaged populations worldwide. The high burden of Type 2 diabetes (T2D) contributes significantly to disability, reduced quality of life, and increased use of health care services, impacting heavily on both individuals and health systems. Potentially effective interventions for the prevention and management of T2D exist and self-management is a core strategy. However, there is limited knowledge on the processes and actors required for the provision of adequate self-management support to compliment routine primary care, especially for disadvantaged populations.

Aim: The overall aim is to understand the self-management support processes for type 2 diabetes and pre-diabetes in socioeconomically disadvantaged communities in Stockholm, Sweden. Specific research questions in turn focus on perceptions about self-management and pre-diabetes, the role of the community in the provision of self-management support and the opportunities for improving community involvement.

Methods: The thesis comprises of four sub-studies, with studies I to III focusing on the individuals, the community and primary care in Sweden. A range of qualitative data collection methods were applied including: individual interviews, natural group discussions, and observations followed by thematic and content analysis. In study IV, a case-study approach was used, including synthesis and triangulation of data from Sweden, South Africa and Uganda, and informed by a self-management framework.

Results: Patients and providers experienced dilemmas in their daily dealings with self-management practices. Whilst patients struggled to adapt to recommended lifestyle changes, providers were ill equipped to manage the cultural diversity of their patients when attempting to empower them to self-manage through education (Study I). Pre-diabetes is not recognized as a diagnosis and persons at risk are uncertain of its significance in everyday life (Study II). Community was perceived as living in close proximity and sharing common resources. Interaction between communities and local and regional stakeholders was limited for health promotion and prevention activities including for T2D (Study III). In comparison to Uganda and South Africa, Sweden has established primary care routines for T2D management but self-management strategies are not adequately tailored to patients' needs, particularly considering the diversity in the target population. In comparison to

South Africa and Uganda, Swedish primary care has no established processes to engage communities in self-management support activities. Examples of this in South Africa and Uganda include integrated care through community health workers and other tailored peer or professional-led support initiatives. (Study IV).

Conclusions: Self-management support is a complex process involving multiple actions and actors. The findings of this thesis highlighted: the mismatches in patient-provider perceptions of self-management; the barriers to recognizing pre-diabetes as the focus of a prevention strategy; the need to redefine the role of communities in the provision of self-management support; and that strengthened ties between communities and primary care, as seen in other settings, has the potential to improve self-management. This further highlights the significance of a contextualized response to the demands of a changing population to ensure that no one is left behind.

LIST OF SCIENTIFIC PAPERS

- I. Aweko J, De Man J, Absetz P, Östenson C-G, Peterson SS, Alvesson HM, Daivadanam M. Patient and Provider Dilemmas of Type 2 Diabetes Self-Management: A Qualitative Study in Socioeconomically Disadvantaged Communities in Stockholm. *Int J Environ Res Public Health*. 2018; 15(9):1810.
- II. Aweko J, Östenson C-G, Peterson SS, Masupe T, Mayega RW, Daivadanam M, Alvesson HM. It's not diabetes but a step closer: Perceptions of pre-diabetes among newly diagnosed persons in Socioeconomically disadvantaged communities in Stockholm. (Manuscript)
- III. Al-Murani F, Aweko J, Nordin I, Delobelle P, Kasujja FX, Östenson C-G, Peterson SS, Daivadanam M, Alvesson HM. Community and stakeholder engagement in the prevention and management of type 2 diabetes: A qualitative study in socioeconomically disadvantaged suburbs in Stockholm. *Global Health Action*. 2019:21.
- IV. De Man J, Aweko J, Daivadanam M, Alvesson HM, Delobelle P, Mayega RW, Östenson C-G, Kirunda B, Kasujja FX, Guwattude D, Puoane T, Sanders D, Peterson S, Tomson G, Sundberg C-J, Absetz P, Van Olmen J. Diabetes self-management in three different income settings: Cross-learning of barriers and opportunities. *PLoS ONE*. 2019 14(3).

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LIST OF ABBREVIATIONS

CCM	The Chronic Care Model
CNI	The Care Need Index
ECCM	The Expanded Chronic Care Model
GPs	General Practitioners
HBA1c	Hemoglobin A1c
LMIC	Low- and Middle- Income Countries
NCDs	Non-Communicable diseases
NGO	Non-Governmental Organization
PHC	Primary Health Care
SDT	The Self-Determination Theory
SM	Self-Management
SMART2D	Self-Management And Reciprocal learning for Type 2 Diabetes
T2D	Type 2 Diabetes
USD	United States Dollars

1 BACKGROUND

1.1 BURDEN OF TYPE 2 DIABETES (T2D) AND PRE-DIABETES

Diabetes and pre-diabetes together represent a growing public health challenge worldwide [1]. Diabetes is characterized by hyperglycemia, resulting from the body's inability to produce any or enough of the insulin hormone or use insulin effectively [2]. Pre-diabetes is a state of increased risk of T2D characterized by blood glucose levels above normal but below the T2D diagnostic threshold when fasting (impaired fasting glucose) or eating (impaired glucose tolerance) or both [3, 4]. Although the annual conversion of pre-diabetes to T2D varies across countries (5%-10% in a year) [3, 5], up to 70% of individuals with pre-diabetes ultimately develop diabetes in 5-10 years [4, 6]. People with diabetes and pre-diabetes are likely to develop complications such as cardiovascular disease, neuropathy, retinopathy and loss of limbs if not properly managed [4]. Such complications contribute significantly to disability, reduced quality of life, and increased use of health care services, which consequently impart a heavy burden on both individuals and health systems [1, 7].

The number of people with diabetes is expected to increase from 425 million in 2017 to 629 million by 2045, an increase of nearly 50% [1]. Furthermore, persons with pre-diabetes are also estimated to rise from 7% to 8% by 2045 [1]. Although an increase in T2D is expected worldwide, Sub-Saharan Africa is expected to be the most affected with a more than 100% increase, whereas North America, the Caribbean and Europe are expected to experience the least change [1, 8]. Of additional concern is that of all the cases of diabetes, half are undiagnosed [1, 8]. Eighty percent of people with diabetes live in low- and middle-income countries (LMICs), but low-income countries in Africa have the highest estimated proportion of undiagnosed diabetes (78%) [1]. Even though Europe is one of the regions with the smallest expected rise in diabetes, the overall burden of diabetes is high with up to 7% of the population being affected and approximately 37% undiagnosed [1].

T2D is the most common form of diabetes and accounts for 90% of all cases, with type 1 diabetes accounting for the remaining 10% [1]. Type 1 diabetes is predominant among children and adolescent populations of European origin and the number of cases stands at over a million [1, 8].

The burden of T2D together with other Non-Communicable Diseases (NCDs) negatively impacts economic growth at the global and national level by adversely affecting workers'

productivity and diverting resources from productive purposes to treating disease [9]. The economic cost of diabetes is increasing over time both for the individual and health systems mainly due to complications such as cardiovascular disease, end-stage renal disease and foot amputation [1, 10, 11]. The health expenditure of people with diabetes worldwide has grown from USD 232 billion in 2007 to USD 727 billion in 2017 for those aged 20-79 years [1]. By 2045, the expenditure on people with T2D is projected to reach USD 776 billion (20-79 years) [1].

It is currently challenging for health systems worldwide to diagnose and manage diabetes effectively. Early detection of T2D and pre-diabetes provides health systems with an opportunity for early intervention in order to prevent T2D complications, or even reverse the progression of disease. However, this opportunity is often acknowledged but not capitalized upon. The diagnosis of diabetes and pre-diabetes is commonly achieved via a fasting plasma glucose test [6]. The pre-diabetes range is between 5.5 mmol/L and 6.9 mmol/L or 42 - 47 mmol/mol with a HBA1c test [6]. While the diagnostic cut-offs for T2D are ≥ 7 mmol/L with fasting plasma glucose test or the HBA1c values of ≥ 48 mmol/mol [6]. Pre-diabetes and T2D have similar risk factors including: overweight and obesity, family history, hypertension, hyperlipidaemia, physical inactivity, smoking, alcohol consumption and previous gestational diabetes [12, 13]. lifestyle modification and key in the prevention of T2D and its complications [13].

1.1.1 T2D and social determinants of health

People with lower education and economic status, including immigrants, are increasingly exposed to T2D risks and are disproportionately affected by T2D [14, 15]. Research has shown that T2D prevalence, incidence and mortality rates are much higher among migrants than the native population in host countries [16] In Sweden, where the research studies were conducted, immigrants - particularly of non-European background - have been found to have 2 to 3 times higher risk of developing diabetes compared to the native Swedish population [12, 17] [18]. Increased risk among this population is attributed to family history of diabetes, unhealthy lifestyle, and migration, psychosocial and socioeconomic factors [17, 19-21]. The NCDs Alliance report on the management of NCDs points out the need to address the social determinants of NCDs as a means to eradicate poverty and foster a more equitable society that supports sustainable development [9]. This involves reaching out to disadvantaged populations using holistic preventive and management approaches to tackle the root causes of T2D [9].

1.1.2 T2D and the Sustainable Development Goals (SDGs)

Addressing T2D and other NCDs is suggested to be fundamental in ensuring progress across the three pillars of economic growth, social equity, and environmental protection with the ultimate goal of achieving sustainable development [9].

Research on management of T2D directly and indirectly contributes to achieving at least 11 of the 17 SDGs, including: 1 & 2: Poverty, hunger & nutrition, 3: Health & well-being, 4: Knowledge & skills for sustainable lifestyle, 11: Access to green & public spaces and 17: multi-stakeholder partnerships. However, goal 3, to enhance healthy lives and promote wellbeing for all at all ages targeting a one third reduction of premature mortality from NCDs by 2030, is the most relevant [8, 22].

The focus on socioeconomically disadvantaged populations and migrant groups with T2D or at increased risk of T2D builds on the knowledge and identification of strategies for provision of equitable and quality healthcare for vulnerable groups and ensuring that no one is left behind [23]. Research on the role of the community and its engagement in health promotion and T2D prevention also contributes to sustainable health care through expanding care networks beyond the formal health system. Research partnerships between multidisciplinary teams across countries promote reciprocal learning and contributed to the building of inter-sectoral & inter professional corporations which contributes to one of the targets of SDG 17 [24]. Overall, the project studies have also enhanced knowledge and skills for sustainable lifestyles for persons with T2D or at risk of T2D further contributing to sustainable development goal 4, ensure inclusive and equitable quality education and promote lifelong learning opportunities for all [24].

1.2 PREVENTION AND MANAGEMENT OF T2D

To a large degree T2D is preventable and effective interventions for the delay of diabetes and its complications exist [25-27]. Evidence from randomized controlled trials in Europe [26, 28] and the USA [29] have demonstrated that lifestyle modification following counselling on healthy diet and regular physical activity can reduce the risk of diabetes by 58% in high risk persons over a 3-5 year period [25, 30]. Meanwhile, pharmacological interventions reduce the risk by 31% [30]. The American Diabetes Association recommends intensive behavioral lifestyle intervention programs for persons with pre-diabetes in order to achieve and maintain a 7% loss of initial body weight and increase moderate-intensity physical activity (such as brisk walking) to at least 150 min/week [6]. Accumulating evidence also suggests potential benefits of pharmacotherapy with metformin for prevention of type 2 diabetes among persons with pre-diabetes [30], particularly for persons with BMI ≥ 35 kg/m², and those aged <60 years [6].

Despite the compelling evidence on the effectiveness of lifestyle interventions for persons at T2D risk, there is inadequate knowledge about the contextualization of these interventions to socioeconomically disadvantaged populations who are disproportionately affected [12, 31, 32]. Pre-diabetes is asymptomatic and mainly detected through a blood glucose test and most persons are unaware of their condition. It has been found that unawareness of T2D risk and risk factors [33], uncertainty about pre-diabetes as a diagnosis [34], insufficient knowledge about the future development of T2D [35, 36] and difficulties in lifestyle modification [37] are major challenges associated with pre-diabetes. In one of the studies looking at participants' experiences of lifestyle change and own responsibility following a diabetes prevention intervention, Jallinoja and colleagues found that lifestyle change was perceived as a constant struggle and that support was required [37]. Additionally, variations in the interpretation and use of the term pre-diabetes during risk communication have also been reported among health professionals and patients [38-40] and these variations in perceptions consequently affect patients' compliance to lifestyle advice [39]. Understanding patients' perspectives and experiences of living with pre-diabetes is critical in the development and adaptation of lifestyle modification interventions for persons at risk of T2D. However, there is limited research on the perspectives of socioeconomically disadvantaged populations with diverse backgrounds.

1.3 SELF-MANAGEMENT OF T2D AND PRE-DIABETES

Self-management is the core strategy for T2D treatment [41]. Self-management is to a large extent the responsibility of the patient and is aimed at controlling glycaemia and preventing diabetes-associated complications [41, 42]. It entails that the patient manages several aspects of the disease including: selection and preparation of meals, exercise, self-monitoring of glucose, consulting health-care professionals and making decisions regarding lifestyle choices and to some extent the pharmaceuticals they use themselves on a daily basis [43-46]. Self-management refers to “the ability of the individual, in conjunction with family, community, and healthcare professionals, to manage symptoms, treatments, lifestyle changes, and psychosocial, cultural, and spiritual consequences of health conditions” [47]. This also implies that the individual needs to be pro-active, develop skills and actively assimilate relevant knowledge.

Implementation of self-management remains a challenge for people living with T2D in all countries [26, 48]. Beyond the individuals’ engagement and patient-provider clinical interactions, there is a need for self-management support both at the health facilities and in the patients’ communities [48, 49]. Over the years, self-management has gained more attention and strategies such as empowerment of patients with self-management skills [50] and increasing social support and community engagement have been proposed to be effective in the management of T2D [51-53]. However, there is limited evidence of the acceptability of these strategies in general and in particular among socioeconomically disadvantaged communities with a high proportion of migrants and prevalence of T2D.

1.3.1 Self-management support

‘Self-management support’ is an important strategy to help individuals cope with T2D and reduce the burden of chronic diseases [54, 55]. It is “the systematic provision of education and supportive interventions to increase patients’ skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support” [56]. Self-management is largely implemented within the context in which the individual with T2D lives and peoples’ everyday interactions within a community play an important role in preventing and managing T2D.

Understanding the community context is crucial in tailoring preventive interventions and ensuring community engagement [57, 58]. However, the term community has no standard definition [58-60], and furthermore, the meaning and experience of community have been

found to differ by context [58]. Researchers have made contributions to understanding the concept of community [60-62]. Frazer [63] suggests that community can be seen as a value, bringing together a number of elements including solidarity, commitment, and trust . These values are said to be vital for generating a sense of belonging [64]. MacQueen et al [57] argue that the definition of community comprises five key elements including: Locus, sharing, joint action, social ties, and diversity. Additionally, members of a community should feel part and parcel of the distinct ‘features of social organization’ including networks, norms, and social trust that facilitate coordination and cooperation for mutual benefit [60, 61]. Recent research has shown that several aspects of the structural and functional characteristics of a social network are associated with increased incidence and prevalence of T2D [65] while certain aspects of social network and social interaction can prevent T2D[66].

Liaison with the community is suggested to facilitate access to and improve the quality and cultural competence of medical care, with an emphasis on preventive and primary care [67]. In settings with a high proportion of immigrants and high prevalence of T2D, the research focus has generally been on understanding T2D care at primary health care (PHC) [68-71] with limited focus on the role of community where the individual lives. Research into understanding the meaning of community and its role in the prevention and management of T2D in socioeconomically disadvantaged settings is therefore scarce.

1.3.2 Theoretical approaches

This PhD project is built on the Expanded Chronic Care Model [72] and the Self-determination Theory [73].

1.3.2.1 The Expanded Chronic Care Model (ECCM)

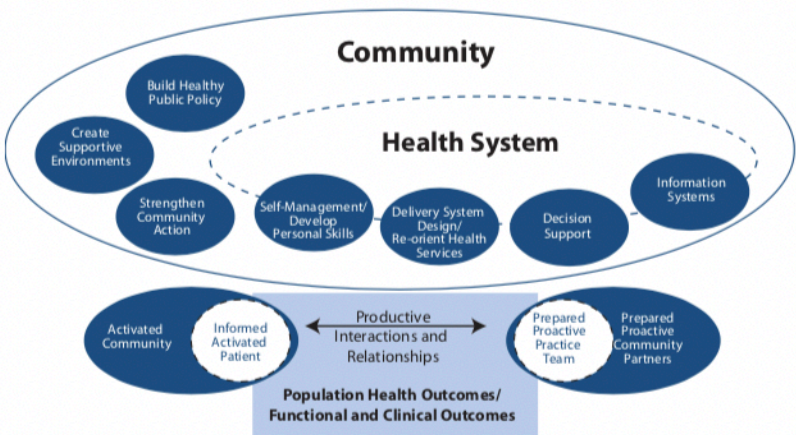


Figure 1: Expanded Chronic Care Model created by Victoria Barr et al (2002) adapted from Glasgow et al (2002) “Does the chronic Care Model also serve as a template for improving prevention” *The Milbank Quarterly*, 79 (4), and the World Health Organization, Health and Welfare Canada and Canadian Public Health Association. (1986). Ottawa Charter of Health promotion.

Self-management is usually assessed within the comprehensive package of care for chronic diseases, using the Chronic Care Model (CCM) [51]. The ECCM is an extension of the CCM which facilitates understanding of self-management and integration of health promotion and prevention [72]. The model looks at self-management and support beyond the formal health system through: development of an individual’s personal skills and capacity to cope with the disease, increased community engagement, and integration of health promotion and prevention strategies to chronic disease care [72]. In *Figure 1*, the inner oval in the ECCM represents the health system within the community (the outer oval). The porous border between the formal health system and the community represents the flow of ideas, resources and people between the community and the health system. The four areas of focus: self-management support, decision support, delivery system design and information systems straddle the border between the health system and the larger community. To address both the delivery of healthcare services and population health promotion, the activities of these four areas can be integrated within, and have an impact on, both the healthcare system and the community [72].

The ECCM recognizes the intrinsic role that the social determinants of T2D play in influencing the individual’s health and emphasizes the extended value of self-management support in coping with the disease as well as development of personal skills for disease prevention. However, this model does not include the individual behavioral mechanisms that play an essential role in self-management. In contrast to the ECCM, behavior change models and theories focus on the individual pathways of behavior but do not include the actors and health system elements. However, self-management and its support requires both the individual and the system perspectives to come together in an integrated and contextually relevant manner.

1.3.2.2 The self-determination theory (SDT)

The Self- Determination Theory (SDT) [73-75] has been applied extensively to health behavior change and is particularly focused on the individual and the processes through which a person acquires the motivation for initiating new health-related behaviors and

maintaining them over time. The SDT suggests people can be proactive and engaged or passive and isolated based on the social conditions in which they develop and function [73]. The theory identifies three distinctive psychological needs i.e., autonomy (the willingness to perform the targeted task), competence also known as self-efficacy (the knowledge and skills to accomplish a the targeted task) and relatedness (sense of belonging and attachment to particular networks) which when fulfilled lead to enhanced self-motivation and when unfulfilled, result in reduced motivation and wellbeing [73]. Self-determination theory suggests focus on two main types of motivation types: extrinsic motivation and intrinsic motivation [73-75]. On one hand is intrinsic motivation which completely self-initiated, it comes from personal interest, curiosity or pleasure of a task [73]. Extrinsic motivation on the other hand is regulated by external sources, the individual's actions are motivated purely by foreseen favorable or unfavorable consequences [75].

1.3.2.3 The SMART2D project

SMART2D is an EU-financed project titled, *A people-centered approach to self-management and reciprocal learning for the prevention and management of type 2 diabetes* [76]. The five-year implementation research project was composed of institutional partners in Sweden, South Africa, Uganda, Belgium and Finland, and three field sites representing under-resourced or disadvantaged areas in three diverse income settings: rural areas in a low-income country (Uganda), urban townships in a middle-income country (South Africa) and socioeconomically disadvantaged suburbs in a high-income country (Sweden) [77]. The overall aim of SMART2D was to strengthen capacity for type 2 diabetes care through proven strategies like task-shifting and expanding care networks in the three settings, specifically, the *implementation and evaluation of* a contextualized self-management approach using facility and community strategies. This thesis relates to the formative phase of SMART2D, primarily in Sweden.

1.4 SOCIOECONOMICALLY DISADVANTAGED AREAS IN SWEDEN

Sweden is a high income country (HIC) in northern Europe with a total area of 528,447 sq. km bordering the Baltic Sea, Gulf of Bothnia, Kattegat and Skagerrak, and neighboring Finland to the east and Norway to the west [78]. The total population in Sweden is approximately 10 million and about 87% of the population live in urban areas [79, 80]. Stockholm, the country's capital and the largest city, accommodates the biggest proportion of the population, with approximately two million residents [81]. Life expectancy for men

and women is 81 years and 84 years, respectively, [81] and the Gross Domestic Product (GDP) per capita is over 50,000 USD [81].

1.4.1 Migration streams and diversity

Over the years, the population in Sweden has increasingly become diverse owing to several streams of migration due to asylum, reunion with close family members, marriage or studies [82]. Like other European countries, the diversity in the cities of Sweden and Stockholm in particular is complex and goes beyond ethnicity (Ref). The suburbs of Stockholm are super diverse and defined by a complex interplay of characteristics including; nationality/country of origin/ethnicity, language, religion, migration channel/legal status, newly arrived immigrant/residency for over a decade, age and gender [83]. In 2010, 1.33 million people or 14.3% of the residents in Sweden were foreign-born. Of these persons, 859,000 (64.6%) were born outside the European Union [84]. Sweden has evolved from a nation of net emigration ending after World War I to a nation of net immigration from World War II onwards. By 2013, immigration had reached its highest peak, with 115,845 people migrating to Sweden [85]. As of 2017, the percentage of inhabitants with a foreign background in Sweden had grown to 24.1% [85]. Inhabitants with a foreign background are defined as individuals either born abroad or having both parents born abroad [81]. The largest foreign-born populations residing in Sweden come from Finland, Iraq, the former Yugoslavia, Poland, Iran, and Syria [81].

1.4.2 The health system

Sweden is divided into 21 county councils/ regions and 290 municipalities [86]. Healthcare in Sweden is publicly financed and the responsibility lies with the county councils and, in some cases, local councils or municipal governments [86] although regulated by the Health and Medical Service Act [87]. The Swedish health policy states that every county council must provide residents with good-quality health and medical care, and work to promote good health for the entire population [86, 88]. The role of the central government is to establish principles and guidelines, and to set the political agenda for health and medical care [89]. The county councils are responsible for the funding and organization of health care, while the municipalities are responsible for meeting the routine care and housing needs of the elderly and people with disabilities [86]. County councils are political bodies whose representatives are elected by county residents every four years on the same day as national general elections [89]). At the county level, there are 70 county

council-driven hospitals, six private hospitals and approximately 1,100 public and private PHC facilities [89].

PHC is the point of entry for persons seeking preventive, curative and rehabilitation services including services for diabetes and other chronic conditions [88]. National guidelines for diabetes care and prevention exist [90]. The guidelines stipulate specific recommendations for counselling and lifestyle modification. They state that healthcare should reach out to socially disadvantaged groups in general, and emphasize the need for culturally adapted self-care programs to cater for different cultural backgrounds, but they lack specific direction as to how this should be achieved [90]. Management protocols for pre-diabetes also exist, focusing on empowerment of persons at risk in order to prevent T2D through education and close follow-up [91, 92]. However, there is limited knowledge of their implementation at PHC centers.

1.5 RATIONALE AND KNOWLEDGE GAP

Although potentially effective interventions for the prevention and management of T2D exist, there is limited research on the adaptability of such interventions to socioeconomically disadvantaged populations. Several studies have shown that implementation of self-management is a challenge and that supporting individuals to self-manage is an important strategy for helping patients cope with and reduce the burden of T2D and other chronic diseases [54, 55, 72]. However, research on the mismatches of self-management from patients' and providers' perspectives is limited. Moreover, increasingly diverse populations can add to the complexities in preventing and managing T2D. Couple with the growing burden of T2D there is a need for a better understanding of the Swedish health system's efforts towards provision of high-quality, equitable care and support to all persons with T2D and those at high risk of T2D. This includes understanding patients' and providers' perceptions of self-management, and exploring the role of community and other stakeholders in the prevention and management of T2D, and incorporating learning from other contexts.

2 AIM AND RESEARCH QUESTIONS

2.1 AIM

To understand the self-management support processes for type 2 diabetes and pre-diabetes in socioeconomically disadvantaged communities in Sweden.

2.2 RESEARCH QUESTIONS

1. What are the perceptions of self-management among persons with T2D born outside Europe and of healthcare providers in socioeconomically disadvantaged communities in Sweden?
2. How is pre-diabetes perceived among persons in socioeconomically disadvantaged communities in Sweden?
3. What constitutes “community” in socioeconomically disadvantaged suburbs in Sweden and how do communities support T2D prevention and management?
4. In comparison to Uganda and South Africa, what are the opportunities to enhance self-management support in Sweden based on the SMART2D self-management framework?

3 METHODS

This thesis is composed of four studies that relate to each other through a conceptual diagram (Figure 2) modified from the ECCM. Studies I, II and III focus on the upper oval of the diagram - interactions between the individual, the community and the health system. Study I seeks to identify the mismatches in perceptions of self-management between healthcare providers and patients with diverse backgrounds. Study II examines the meaning of pre-diabetes among newly diagnosed community members, and study III explores the perceptions of community and its role in the health promotion and prevention of T2DM. Study IV looks at how these interactions and linkages influence self-management and prevention of T2DM. The study uses a multiple-theory based approach to assess the determinants of self-management from the individual within the community to the health system and back to the community, and contrasts these determinants across three different settings in high-, middle- and low-income countries to identify opportunities for self-management improvement in Sweden.

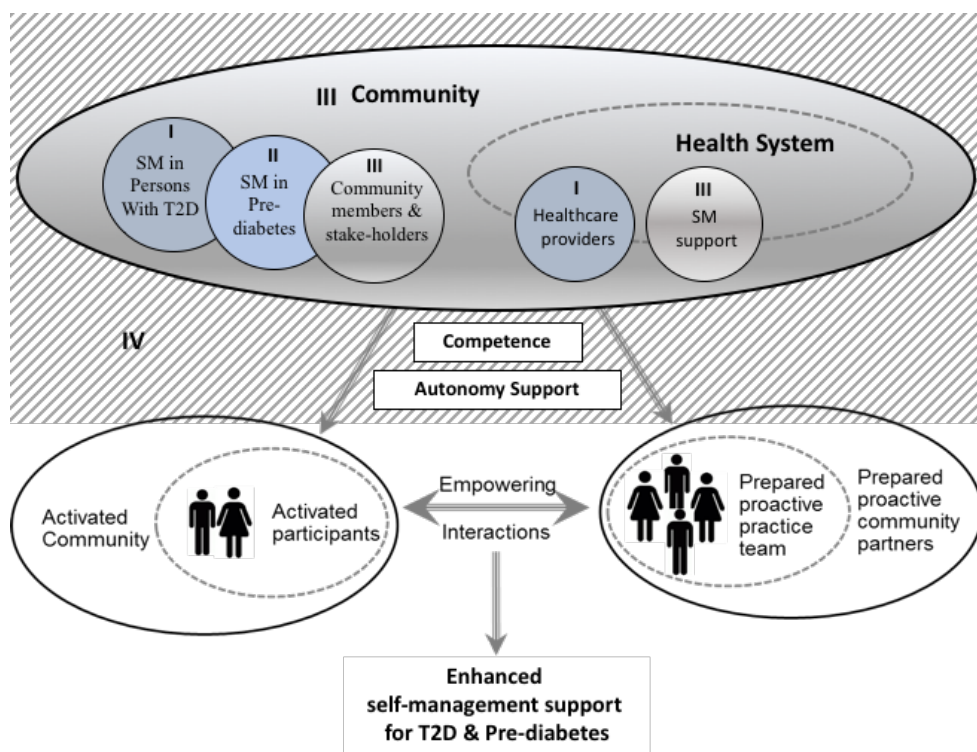


Figure 2: Conceptual diagram for the PhD studies adapted from the Expanded Chronic Care Model by Barr et al, 2003

3.1 STUDY DESIGN

Figure 3 outlines the study topics, research questions and the target population that feed into the four studies. Primary data collection was conducted for studies I, II and III. Data for study IV was based on data synthesis from the first three studies, using a self-management framework.

Self-management support processes for type 2 diabetes and pre-diabetes

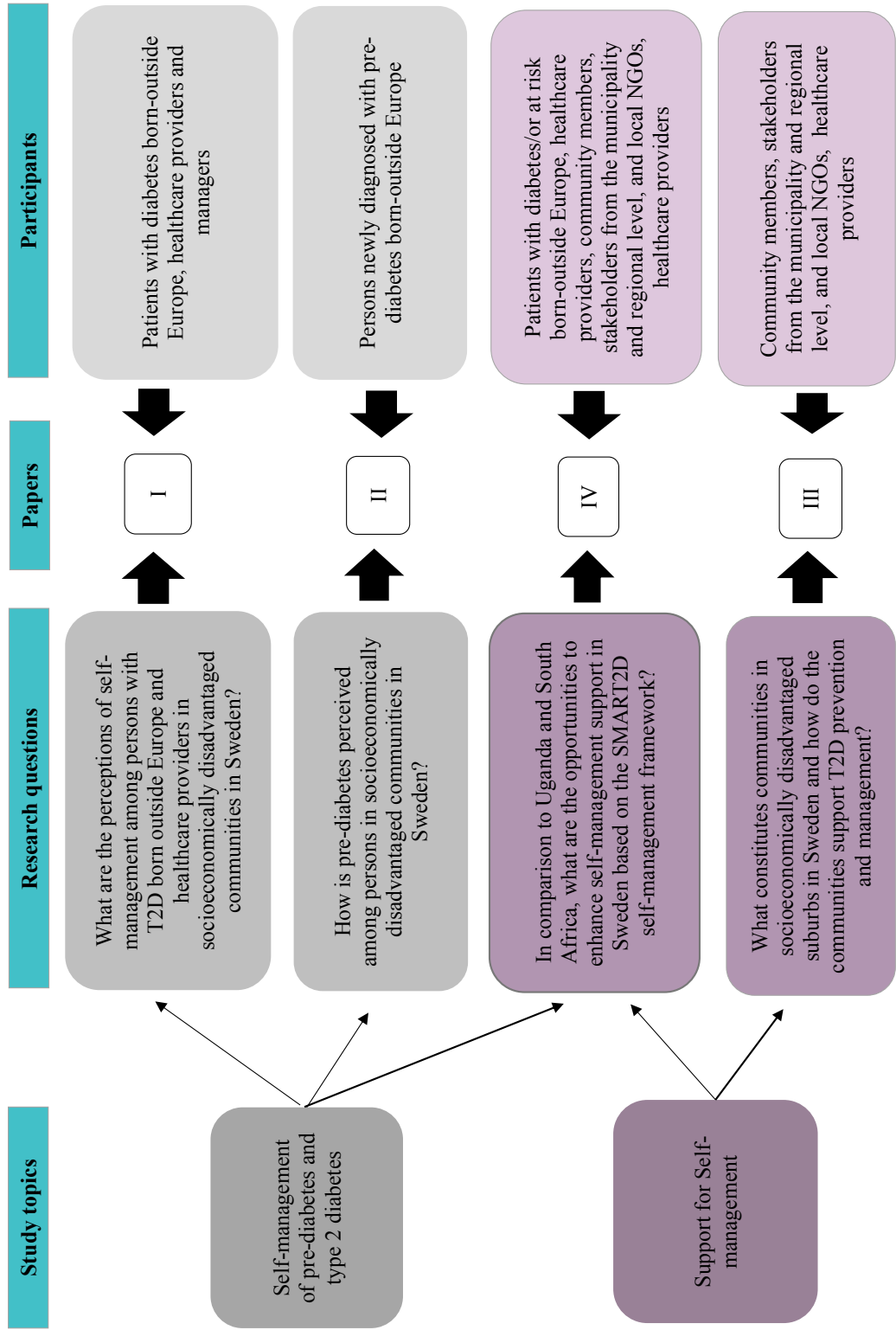


Figure 3. An overview of the study topics, research questions and study participants

A range of qualitative research methods were applied in the PhD project. Individual interviews [93], natural group discussions [94], and observations were used to answer the research questions in studies I, II and III. In study IV, a case-study approach [95] informed by a framework was used. Each of these methods will be described in detail in the subsequent sub-sections in the order they were carried out.

3.2 STUDY SETTING

The studies were conducted in five socioeconomically disadvantaged suburbs together with their PHC centers located in three municipalities in Stockholm region (*see figure 4*). The PHC centers were purposely selected based on their involvement in the SMART2D project, their engagement in a diabetes screening program run by the 4D project jointly managed by Karolinska Institutet and Stockholm County Council [96] and their willingness to participate in the studies. The municipalities are anonymized for confidentiality purposes in order to secure participation.

The populations in the municipalities are between 75 000 and 100 000 people [81] with the share of persons born outside Sweden being between 25% - 30%. These represent a mix of nationals mainly from countries in the Middle East (mainly Syria and Iraq) Africa (Somalia and Eritrea) and South America (Chile) [85]. The residents in the suburbs also include native Swedes and residents from other European countries (mostly Finland) [79].

The burden of disease including T2D is generally higher in these areas than in the Stockholm region as a whole (12-16% in adults 65 years and older compared to 5%) [97]. Additionally, compared to central Stockholm, the socio-economic status of the selected communities within these municipalities is defined by low education, poor housing and low-income, high unemployment and high healthcare needs [98, 99].

Communities can be described in multiple ways and the Care Need Index (CNI) is one way used to estimate the level of deprivation [100]. The CNI is based on the socio-demographic characteristics of neighborhoods, i.e., the proportions of elderly people living alone, children under the age of 5 years, residents who are unemployed, residents who have a low educational level, single parents, and residents born outside Western countries as well as high rates of mobility and higher risk for ill health [100, 101]. Our study settings are categorized as deprived due to high CNI scores in comparison to affluent neighborhoods in the Stockholm region [79].

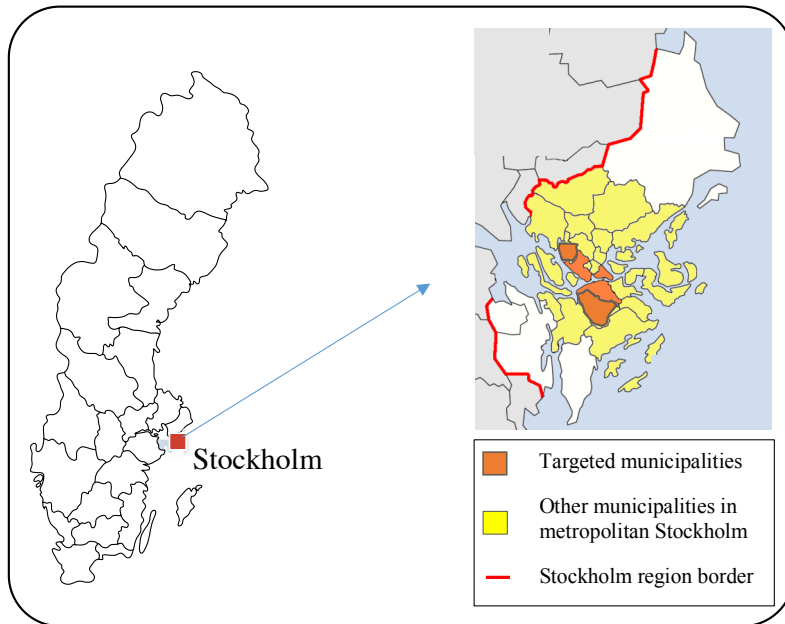


Figure 4: Map of Sweden and the respective municipalities where the studies were conducted in Region Stockholm

Diagnosis and management of T2D is provided at the PHC centers along with health promotion, disease prevention, curative care and rehabilitation; type 1 diabetes care is given at outpatient centres in hospitals [88, 102, 103].

All members of the population are listed in the PHC of their choice and these are often within the local residential areas [103]. T2D treatment is provided by teams of 2-3 health professionals including General practitioners (GPs) and nurses specialized in diabetes care [101]. All listed patients with T2D receive subsidized care with two annual follow-up visits [101], one visit with a doctor for structured individual tests including HbA1c, cholesterol and blood pressure and the other with a diabetes nurse for lifestyle education [101]. Patient referrals to secondary and tertiary care (e.g. for lifestyle consultations, ophthalmologists, endocrinologists and nephrologists) are based on need [101].

3.3 STUDY PARTICIPANTS

Participants were recruited from the PHC centers and the community at large (*see Table 1*). Participants purposively sampled from the participating PHC centers included men and women aged 35-75 years with T2D/ or pre-diabetes, health providers and health managers. Also recruited were community members active in formal and informal groups, representatives from local government, local NGOs and regional institutions.

Table 1: Study participants				
Participant types	Number of participants		Data collection method (Number)	Studies using the data set
	Male	Female		
Persons with T2D	6	6	Individual interviews (N=12, recorded)	I, III & IV
Healthcare providers	1	6	Group interviews (N=3, recorded)	I, III & IV
Primary Health Center Managers	1	3	Group interviews (N=1, recorded)	I, III & IV
Persons with pre-diabetes	8	9	Individual interviews (N=17, recorded)	II
Community members				
- Informal group leader - Community members active in a formal network	6	2	Group interviews (N=4, 2 informal unrecorded)	III & IV
- Gym manager - Local shop owners - Formal group leader - Community member active in a formal network - Community members active in an informal group	9	5	Individual interviews (N=14, 6 informal unrecorded)	III & IV
Local and regional stakeholders				

Local/Municipality level - Development strategist - Prevention coordinator - Social worker - Swedish language teacher - Member of the Swedish Diabetes Association - Manager at Organization of diversity promotion work - Manager at Transcultural center Regional Level - Health educator (Region Stockholm)	4	4	Individual interviews (N=8, recorded)	III & IV
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The participants with T2D were identified and sequentially selected from patient datasets at the PHC centers in two stages with the purpose of understanding their experiences of self-management. In the first part, individuals who had been diagnosed with T2D in the last six months and had lived in Sweden for at least five years were recruited from two PHC centers where, at the time, diabetes screening was being conducted. The participants were contacted by a diabetes nurse and interested participants were scheduled for interviews with research team members. After preliminary analysis, additional participants were selected from the three other healthcare centers to include individuals who had lived with a diabetes diagnosis for more than five years. The selection criteria for additional participants was aimed at obtaining more variation in the perception of self-management in terms of period lived with diabetes (Study I).

Doctors and nurses specialized in T2D and having regular contact with T2D patients, and the health managers of the respective PHC centers were also invited to participate in the study. The purpose of this was to understand self-management as practiced by patients at the five health centers and the structure of diabetes care including patients' journeys from the community to the health center and subsequent referral to tertiary care. In total, twelve patients of Asian (Pakistan, Iran, Turkey and Syria), South American (Chile) and African descent (Eritrea and Ivory Coast) participated. Seven providers (including, doctors and nurses) and four managers also took part (see Table 1). The providers were born in Sweden except for three (one born in Africa, one in South America and the other in Middle East) (Study I).

Participants with pre-diabetes were purposively sampled from a dataset of recently screened persons at two PHC centers in order to understand their views about pre-diabetes. Selection of the participants was based on predefined criteria for maximum variation: (a) Men and women

aged 30-75 years and born outside Europe, (b) diagnosed with pre-diabetes in the last 12 months and (c) lived in Sweden for at least five years. Diabetes nurses at the health centers contacted eligible participants to inquire about interest in participating and the research team continued with the details of setting up a time and place for the interview. In total, 17 men and women with a pre-diabetes diagnosis, mainly from Asia (Iraq, Iran, Bangladesh, Pakistan and Turkey), Africa (Benin and Morocco) and South America (Uruguay and Chile), participated (Study II).

Community members were purposively sampled in order to understand their perceptions of the notion of community and their interaction with other stakeholders (local government, local NGOs and regional institutions). Selection of these participants followed a step-wise approach which began with the gathering of local community associations through internet sources, the civil offices (Medborgarkontor) and through word of mouth. Through the research team's prolonged engagement in the community (February - November 2015) [94], gate-keepers were identified to assist with access to community groups which were not listed on the internet. Using snowball sampling, 22 community members were recruited for the interviews. These included men and women, mainly from the Middle East (Turkey, Iran, Iraq, and Syria) and Africa (Somalia, Ethiopia, and Eritrea), who had lived in Sweden for five years or longer.

Health providers, specialized in T2D care and who had regular contact with T2D patients, and health managers were also interviewed to understand their perceptions of T2D prevention and administration of care in their respective health centers and their collaboration with community and other stakeholders in diabetes prevention interaction. In total, seven providers and four managers were interviewed. The final category comprised of eight representatives from local government, local NGOs and regional institutions including the municipalities and Stockholm region, purposively selected to share their experiences and strategies of engaging with socioeconomically disadvantaged communities in the prevention and management of NCDs (Study III).

Data from the first three studies were synthesized together with site specific data from SMART2D sites in Uganda and South Africa and literature on self-management in the respective sites (Study IV).

3.4 DATA COLLECTION

Data for the studies was collected simultaneously between July 2015 and October 2016 by JA together with a multidisciplinary team of researchers from the SMART2D project. Each team member was assigned different tasks and took part in meetings and discussions. Data was collected by different team members depending on language skills and background. JA led data collection of studies I and II and parts (provider interviews) of study III and synthesis of data from Sweden for study IV.

3.4.1 Individual interviews

Context in data collection matters as it is important for participants to not feel threatened or prevented from talking during an interview [104]. Thus the preference of the participants was important to accommodate. In the present setting, the choice of individual versus natural group discussions was based on the participant's convenience and requirements. Participants with T2D and pre-diabetes in study I and II were individually interviewed based on their requirements in terms of time and venue for the interviews. The interview venues ranged from participants' homes to cafes within the local neighborhoods. Stakeholders from local and regional authorities and NGOs and formal network leaders in study II were individually interviewed because they were difficult to access. Formal network leaders were only accessed with the assistance of a gatekeeper [93], a resident of the area and a known member of the local networks. Whilst some of the interviews with network leaders were formal, others took the form of informal conversations and were not recorded. Instead, a journal was kept with detailed notes of each conversation. These notes were later typed and files stored on Own Cloud. Of the interviews with stakeholders from local and regional authorities and NGOs, two interviews were conducted by telephone as the participants were time constrained. Separate semi-structured interview guides were used for the different groups of study participants (see appendices 1, 2 and 5).

The interviews were conducted in the language of the participants' choice, mostly in easy Swedish language (more of descriptive sentences with limited vocabulary), English and Arabic. In two cases, interpreters were used to translate Persian to Swedish for a participant who only spoke Persian, and Swedish to English as one of the data collectors was not conversant with the Swedish language. Field notes were also taken during each interview to aid understanding of the interview data and member checks were conducted for all interviews

in order to seek clarification and affirm the meaning of responses [94]. All the individual interviews were recorded except six with community members in study III who declined.

3.4.2 Group interviews

Natural group discussions were used when individual interviews were not possible due lack of time on the part of participants or when participants preferred to participate within their “natural group” [94], which were working teams in the case of the health providers at the PHC centers, language classes or NGO activities such as a women only sewing group. Natural groups facilitate interaction between the participants who are familiar with each other [94]. The providers in study I and III were interviewed at the health centers in their working teams which comprised groups of 2–3 participants per session. The managers were also interviewed in a group of three participants during a managers’ meeting at the county council. One of the managers, who was not present at the meeting, was individually interviewed. Natural group discussions were convenient for the providers. They expressed interest in sharing their experiences in their working teams and gave us an opportunity to listen to the discussions between the nurses and doctors. Two of the research team members moderated the interviews with the providers.

All recorded individual and group interviews lasted between 43 and 90 minutes. The unrecorded discussions were much shorter. The interview guides used are attached (see Appendices 3 and 4). The interviews in Swedish and English were transcribed verbatim. Those held in Arabic were immediately translated to English during transcription.

3.4.3 Field observations

My engagement in field work started in 2015. The first part involved meeting community stakeholders and local partners and data collection. I then took part in screening and the implementation of the trial. I took notes on observations made in the communities throughout the process. Data collection was ethnographic in nature [94] using observations of the community activities to understand the meaning of community (Study III). This involved approximately four months of field work by FA & JA. During this time, the team visited formal community networks including several ethnic associations, Swedish language classes, local gyms, local NGOs, and informal networks - often male only/female only groups. Other places visited included the civil offices within the communities, PHC centers and regional health institutions. Rapport was established with community members and leaders of local

groups with support from a gatekeeper. A journal of field memos and notes [94] from observations of everyday community life at private and public meeting points was kept and used to supplement the interview data in study II.

The same data from interviews, focus group discussions, and observations was re-analyzed and synthesized in paper IV together with site-specific data from Uganda [105] and South Africa [106]. Additional secondary data from literature, including national statistics, findings from other studies, and project documents, were also included.

3.5 DATA ANALYSIS

Different qualitative methods were used to analyze the data in the four studies. Data in studies I and II were analyzed using thematic analysis [107, 108]. Thematic analysis is the process of identifying, analyzing and reporting patterns (themes) within data [107]. The reason for using thematic analysis was based on its suitability in interpreting individual perceptions and lived experiences and its ability to decode the complexities of meanings within data [108]. Analysis of the data was conducted by a multidisciplinary team comprised of two health systems researchers with backgrounds in nutrition (JA) and public health (IN), an intervention and implementation research expert (MD) and a medical anthropologist (HMA). The team had prior experience of working in both European and Non-European settings and provided a blend of insider-outsider perspectives during the analysis. Additional expertise and perspectives required for each of the papers was provided by other co-authors (C-GO, SSP)

In study I, the data was firstly subjected to preliminary analysis, involving coding of the first three interview transcripts using Nvivo software version 11 to develop a coding list that was applied to the remainder of the transcripts. The analysis process was iterative with back and forth movement between the codes and the data to refine the codes and to ensure that they remained grounded to the data. In the second step, similar codes were clustered into categories and these were compared and contrasted between the three sets of participants to identify themes and sub-themes. Peer debriefing was performed through multiple meetings and discussions between the JA, HMA and MD who assessed and refined the themes. As a last step, the findings from all the data sets were compared and contrasted to ascertain differences in the perspectives of patients and providers associated with self- management.

In study II, the data was thematically analysed [108] and as coding and revision of codes progressed, different social theories were consulted in order to better understand the participants' views. The psychometric theory explores both cognitive and emotional dimensions of risk perception in order to capture what meaning is attached to risk [109, 110]. According to the theory, risk is subjectively defined by individuals and influenced by a wide range of psychological, social, institutional, and cultural factors [109, 110]. The theory applies a broad range of domains or characteristics that influence how people perceive or evaluate risk as a dread/non-dread risk. These domains include: 1) previous knowledge about risk, 2) controllability, 3) dread, 4) catastrophic potential of the risk, and 5) severity of the consequences [111]. These were used to interpret participants' perceptions and experiences of pre-diabetes as a state of increased risk for T2D. This was achieved through comparing and contrasting the codes with the theory domains mentioned above to identify similarities and differences. The codes were finally clustered into themes and sub-themes.

For study III, a content analysis approach [112, 113] was used to analyze the data in two steps. In the initial step, coding of the transcripts in their original languages was carried out to glean meaning units that defined community and the interaction between stakeholders. This first step was conducted separately by FA, JA and IN, supported by MD and HMA. In the second step, preliminary codes were compared across the data from the three participant categories by FA, JA and IN and similar codes were grouped into sub-categories and categories, which were later discussed and revised together with MD and HMA during a series of meetings. In order to enhance credibility and trustworthiness, JA examined the transcripts (peer debriefing) [94] from the interviews with the community members, local government, local NGOs and regional institutions, and together the data collection team reached a consensus on the final analysis. Triangulation of data collection methods and participant perspectives was instrumental in this final stage of analysis.

Analysis for study IV proceeded with each of the study sites assigning site-specific data to a set of cross-cutting topics centered on the SMART2D framework elements (i.e., individual characteristics of the study population, the individual mediators, family and friends, the health providers, the community health actors, the health system, the social environment, and the physical environment). Data was first triangulated from different sources including interviews, observations and literature, resulting in country-case descriptions. At the second stage, an excel table was used to systematically chart data from the three sites based on the

above mentioned element of the framework. In the final stage, comparisons were made between and across the countries to identify ‘differences’ or ‘similarities’. This was based on the presence of the elements and their estimated contribution to self-management in a particular context. An element meeting the two criteria in one context and not in another was classified as a difference. If an element met both criteria in two different contexts, it was classified as a similarity. Two co-authors JDM and JVO evaluated each element based on the two criteria mentioned above. In case of disagreement, the elements was discussed with MD and confirmed with the specific country teams.

3.6 ETHICAL CONSIDERATIONS

All four studies were granted formal ethical approval by the Regional Ethics Review Board in Stockholm (Ref. 2015/712-31/1). Ethical approval for the fourth study was also granted by the Higher Degrees, Research and Ethics Committee (HDREC) of Makerere University School of Public Health and the Uganda National Council for Science and Technology (Ref. HDREC-331 and HS 1917), the Senate Research Committee of the University of the Western Cape (Ref. 15/3/17 and BMI7/1/36) and, in Belgium, the Institutional Review Board (ref 993/14). Permission to conduct the study was obtained from the heads of the participating primary healthcare centers. Written informed consent was obtained from all participants in Swedish or in the native language of the individuals. Participants were given an information letter describing the purpose of the study. Confidentiality was ensured as well as the right to terminate their participation in the study at any time without explanation. For participants who are not literate, the information was read to them in Swedish or with the support of an interpreter in the language the participant was comfortable using. Thumbprints were used instead of signature where the participant could not write. All data was anonymized before analysis and accessed by only the research team. Identification codes were used to refer to participants throughout the study. All records were secured in Owncloud, a web-based storage software and accessed by the team members through individual log-ins.

4 MAIN FINDINGS

The results are presented below by study with the respective research questions.

4.1 PATIENT AND PROVIDER DILEMMAS OF T2D SELF-MANAGEMENT

What are the perceptions and experiences of self-management among patients and providers in socioeconomically disadvantaged areas in Sweden?

In study I, two main themes: *Adopting and maintaining new routines through practical and appropriate lifestyle choices* and *Balancing expectations and pre-conceptions of self-management* were identified representing dilemmas inherent in the patients' perceptions and experiences of self-management in everyday life and providers' practice (see table 2).

Adopting and maintaining new routines through practical and appropriate lifestyle choices

For most of the patients, diabetes was perceived as common and part of the aging process, as several of the participants' family members were suffering from the condition. A major dilemma for the patients was the uncertainty about how to fit the diet and physical activity recommendations into their daily routines. Deciding which foods and physical activity was suitable and in what amounts was exceptionally challenging as the lifestyle information the participants had reportedly received from the healthcare providers was not explicit and they therefore lacked structured individual lifestyle plans. Decisions to adopt specific lifestyle practices were based on how simple these were to follow. Some participants for example thought that reducing their intake of sweet foods such as pastries, candy and sugar in tea was easy to do. Others figured that complimenting their daily meals with fruits and vegetables was sufficient. A few others also chose to take short walks after meals as a means to exercise. Older participants however, opted to only take medication to control their blood glucose.

' . . . they told me, you must reduce your food, and exercise a lot . . . They just say you have to do that and that and that, but don't tell you how. I need a plan with information on what to eat. ' (Male with T2D)

For older patients, most of whom had had T2D for a longer time, adhering to the diet and physical activity recommendations was considered to be impossible as they had several coexistent conditions (including heart disease) to deal with.

Balancing expectations and pre-conceptions of self-management

Healthcare providers acknowledged patients' struggles with adherence to lifestyle advice. However, their overall expectation was that self-management is the responsibility of the patient, who is supposed to manage several aspects of the disease with guidance from the providers. The providers faced a dilemma in determining how much of the self-management responsibility should be left to the patient and how much they should intervene. Multiple strategies for dealing with the patients were reported. Some providers perceived their own role as giving patients instructions on what to do to manage their diabetes. Others mentioned that most of the patients do not follow the lifestyle advice recommended to them and attributed this to the patients not taking their condition seriously. A majority of providers thought that self-management tasks were too difficult for the patients who were already dealing with several other socioeconomic concerns including family responsibilities, unemployment and poor accommodation situations. They felt that it was their responsibility to support these patients.

"It is the patient's responsibility, but a difficult one too. I often tell new patients that it is your responsibility but as a physician, you cannot just leave the responsibility to the patient. You cannot just say that it is his responsibility, you have to help them." (Healthcare provider)

These providers reported that they were balancing roles in order to support patients. They switched roles between "expert" and "facilitator" depending on the patient's circumstances. A few providers took on the facilitator role to support mostly the elderly participants and the illiterate. They did this by learning about the cultural food habits of these patients and listening to different patients' opinions about treatment alternatives. Such cultural experiences were reported to be useful in the provision of appropriate lifestyle advice.

'... what I have discovered is, I have patients that have different food habits. So first I have to learn the culture and what they eat, and then I have to be able to give advice. There are Somalis, so you have to be able to learn their food. For example, I did not know that they eat a banana every meal.' (Healthcare provider)

For the other providers, adjusting roles was a challenge. The barriers cited were heavy workloads and limited time for patients. Another challenge reported by the managers was the high staff turn-over in the health centers and lack of adequate resources to provide specialized care to the patients.

Both the patients and providers acknowledged that sustaining the recommended lifestyle changes was challenging for the patients. The providers felt the need to empower their patients to change behavior through education but were not equipped to address the diverse cultural views pertaining to food, physical activity and treatment perceptions that were unfamiliar to them.

'What is problematic then is that, the perception of food, treatment and physical activity is perhaps different from what we are used to.' (Healthcare manger)

Additionally, the health providers were unused to patients being accompanied to clinic visits by close family members such as spouses and children. They could not see the role of accompanying family members in the consultation rooms and in the facility care process. The presence of relatives in the room was often perceived as an inconvenience and the providers were uncertain about how to address relatives and at the same time maintain patient privacy.

Table 2: *A summary of the themes, sub-themes and categories of the participants' data for Study I*

Themes	Sub-themes	Categories
<i>Adopting and maintaining new routines through practical and appropriate lifestyle choices</i>	Diabetes as part of aging and family history	Developing T2D is normal when older (patient) Patients do not perceive diabetes as serious (provider)
<i>Balancing expectations and pre-conceptions of self-management</i>	Tailoring of information and advice to fit daily life	Adopting selective recommendations (patient) Balancing opposing roles of self-management responsibility (provider) Differing views of self-management support

4.2 IT'S NOT DIABETES BUT A STEP CLOSER: PERCEPTIONS OF PRE-DIABETES AMONG NEWLY DIAGNOSED PARTICIPANTS

How is pre-diabetes perceived among persons in socioeconomically disadvantaged communities in Stockholm?

In Study II, three themes were identified representing participant perceptions of pre-diabetes: ***Pre-diabetes is no cause for alarm***; ***realizing that pre-diabetes is a step closer to diabetes***; and ***uncertainty of the significance of pre-diabetes in everyday life*** further elaborated in six sub-themes, with categories summarised in Table 3 below.

Pre-diabetes is no cause for alarm

Pre-diabetes was not perceived as a threat by patients. Based on their previous knowledge of diabetes and its risk factors, the participants felt that pre-diabetes could easily be controlled and thus was no cause for alarm. Pre-diabetes reportedly had no immediate effect on their health or daily routines as participants felt normal and continued to carry out their daily routines as usual. Additionally, no catastrophic potential or danger was attached to pre-diabetes as compared to high blood pressure, for example, which the participants were more worried about.

'So, I haven't got any disease yet, so I just need to fix the food and exercise, so everything should roll on as usual.' (Male participant, interview 10)

Most of the participants were familiar with diabetes through the experiences of close family members and friends suffering from it. Through these encounters, the participants recognized the possibility of developing diabetes in the future due to inherited risk. These participants appreciated the pre-diabetes diagnosis as an opportunity to know their condition before the onset of T2D.

'... I know it's common, everyone has it (diabetes). So, I wasn't surprised. Actually, I was happy because it was not diabetes' (Female participant, interview 2)

Through their personal searches and information from their health providers, some of the participants expressed knowledge about pre-diabetes and the possibility of changing their diagnosis through healthy dietary choices and physical activity. The participants identified personal unhealthy food habits associated to their diagnosis.

Realizing that pre-diabetes is a step closer to diabetes

Some of the participants feared diabetes and interpreted the pre-diabetes diagnosis as being at the edge and a step closer to developing diabetes. Being at the edge meant being at increased at risk of T2D. The pre-diabetes diagnosis was seen as a warning to either change behaviour or get T2D. It triggered participants to reflect on their personal lifestyles and the possibilities to change.

Women with children were specifically concerned about the future risk of T2D. These women dreaded getting diabetes and the likelihood of transmitting the risk to their children. Diabetes was a severe consequence that these participants attached to their pre-diabetes diagnosis and thus most of them were disappointed about their pre-diabetes diagnosis.

'A few years ago, my mother got diabetes. I got scared and thought if I didn't exercise or do anything maybe I could get it too. Now here I am, at risk. I am a bit disappointed, I might give it to my children too' (Female participant, Interview 16)

All participants referred to receiving lifestyle advice from a diabetes nurse aimed at preventing diabetes. However, few recognised the need to change their lifestyle. Attempts to make small dietary and physical activity changes to personal routines were sometimes encouraged by supportive family members.

'My sister usually recommends healthy stuff to me. Sometimes it is exercise like walking or gym or something. She always gives me tips when she finds something new.' (Female participant, interview 10)

Uncertainty of the significance of pre-diabetes in everyday life

The term pre-diabetes was met with uncertainty and confusion with regard whether it is a risk or condition, and what significance it had to everyday life. Most participants were aware of their increased risk of developing T2D but could not understand that pre-diabetes was a diagnosis. Pre-diabetes appeared as an unknown as the participants demonstrated limited knowledge of the severity of pre-diabetes as a high-risk state. The participants were only aware of the diabetes diagnosis, which was either a positive or negative blood glucose test with no intermediate state.

‘What I have always known is that if you go there (the clinic) for a blood test like diabetes for example, you are told either you have diabetes or not. It is the first time I am hearing the word pre-diabetes, this is only in Sweden.’ (Male participant, interview 7)

Limited contact with and follow up by healthcare providers after diagnosis and lack of sufficient knowledge and communication about the pre-diabetes diagnosis and its management also contributed to participants’ uncertainties about pre-diabetes. The need for further guidance in terms of specific lifestyle modification plans and monitoring of progress after a pre-diabetes diagnosis was expressed.

Table 3: A summary of the themes, sub-themes and categories of the participants’ data for Study II

<i>Themes</i>	<i>Sub-themes</i>	<i>Categories</i>
<i>Pre-diabetes is no cause for alarm</i>	Perceiving diagnosis as not serious	Diagnosis not recognized as a condition
<i>Realizing that pre-diabetes is step closer to diabetes</i>	Coming face to face with reality of being at risk	Acknowledging risk as a step closer to diabetes
<i>Uncertainty of pre-diabetes’ significance in everyday life</i>	Unfamiliar with the term pre-diabetes	Denying pre-diabetes as a diagnosis

4.3 COMMUNITY AND STAKEHOLDERS’ ENGAGEMENT IN THE PREVENTION AND MANAGEMENT OF T2D

What constitutes communities in socioeconomically disadvantaged suburbs and how do they support T2D prevention and management?

In study III, two main themes were identified: ***Finding common ground to address the complex diversity within the community***, and ***Mismatch between awareness of community’s needs and available skills and resources***. The themes are informed by sub-themes and categories shown in Table 4 below.

Finding common ground to address the complex diversity within community

This theme captures participants' understanding of the notion of community. Community meant living in close proximity and caring for one another. The participants referred to their local communities as areas geographically demarcated and distinct from the rest of the Stockholm region. There were no clearly defined social and cultural boundaries within the communities. Having a common understanding among community members was believed to be far more important than having the same nationality and religion. Despite diversity in culture, nationality, religion, and language, living in the same neighborhood facilitated a common understanding between community members, bringing a sense of cohesion and belonging. In this way, community members were responsible for each other's needs and supportive of one another.

'People here live very collectively. We share a lot of stuff. Neighbors knock on each other's door. Like [borrowing] the SL card (travel card), everything is sharing and caring mentality. And you don't care, you just knock and you're like "Can I borrow..."' (Female community member in formal network)

The communities comprised of several formal and informal networks in which an individual community member would be active in a few. These often brought together members of the same gender, language and similar ethnic backgrounds. Informal small groups held their meetings in public places such as cafes or shopping areas. The formally established groups included ethnic associations, language classes, sports clubs, women only groups organized by local NGOs and religious groups. While there are a number of groups that are organized around the country of origin of members, such as the Somali and Kurdish organizations, the women's groups such as the sewing group, catering group, and language class are driven by activities and interests. Members of these groups tend to represent multiple languages, cultures, religions and countries of origin. None of the groups had any formal restrictions on who could join.

Access to these community groups by outsiders, i.e., people not living in these areas, including representatives of public authorities, NGOs and research institutions, was difficult without assistance from gatekeepers.

'Today they often say we shouldn't speak as "we" and "them". But we have to recognize there is a "we" and "them". In every term. In terms of school, housing, criminality and so on.' (Male community member active in a formal network)

The community members expressed a low level of trust towards outsiders from or affiliated with public authorities. They were well-aware of living in socioeconomically disadvantaged

areas and noted that they are also seen as such by outsiders. The community members' lack of trust in authorities was echoed by participants from local government who also noted that in the healthcare domain, some community members were concerned about not being understood and not receiving appropriate care in the local healthcare centers. In order to regain the community members' trust, it was highlighted that time and resources are needed.

'...you have to work really hard and it is very much about... personal relationships, you have to build relationships...if someone trusts you in this area, then that person will trust others that you refer them to. You must somehow have ambassadors or key persons within the ethnic groups that are respected by the people. So, you have to work actively in the area. It does not work to come in as a stranger and believe that it will work.' (Male representative from civic office at the Municipality).

All the stakeholders recognized that the communities were culturally heterogeneous and diverse in their beliefs pertaining to lifestyle habits and health needs compared to other areas of Stockholm. It was difficult for them to identify strategies to work with groups unfamiliar to them.

Mismatch between awareness of community's needs and available skills and resources

The theme reflects the dilemmas and barriers the participants expressed in relation to engagement in NCDs prevention.

The community members reported many social problems requiring attention and T2D risk was only one of them. It was argued that strategies for addressing health behavior needed to be integrated with other social and welfare programs.

'... The socio-economic difference and I mean the socio-economic class is really low here... So the unevenness in the resources can have an influence on health or lifestyle... you have to change other things in order to be able to change lifestyle and healthcare. I don't think you can just go and ask people to change, you have to address the root cause of their current behavior.' (Female community member active in a formal network)

Culturally adapted health promotion and diabetes prevention approaches and information materials were mentioned as important. Some stakeholders expressed a need for better knowledge and understanding of the different cultural and social traditions as a way to increase utilization of offered services.

'I think one of the biggest problems here is that different ethnic groups are seen as one minority group...but it is not like that. Even in a country like Iraq, for example, there are several different cultural groups with different codes, traditions, and religions, so I think it is very important to know and understand the cultural differences.' (Male representative from the Region Stockholm)

Although there was increased awareness of T2D risk and the need to address it in a culturally appropriate way, formal responsibility for collaboration between stakeholders to prevent T2D was lacking. Most of the local government institutions and stakeholders work in “silos” with a narrow focus and limited resources available for health promotion and T2D prevention. The civil offices for example, were involved in health promotion at community level, but only focused on drugs and crime prevention.

The need for better collaboration between formal institutions and the local community associations, mosques, churches and social groups was expressed. Specific suggestions for culturally adapted health information on T2D and other NCDs included provision of brochures translated to local languages.

Table 4: A summary of the themes, sub-themes and categories of the content analysis of the participants' data for Study III

<i>Themes</i>	<i>Sub-themes</i>	<i>Categories</i>
<i>Finding common ground to address the complex diversity within the community</i>	Sharing a sense of belonging to a local community	Coming together through shared beliefs, values and resources
	Recognizing social and cultural diversity	Culturally diverse ethnic groups represented by formal and informal networks
<i>Mismatch between awareness of community's needs and available skills and resources</i>	Lack of formal responsibility for collaboration between stakeholders	Limited focus and resources for collaborations between health centers and community groups for health promotion and prevention
	Increased awareness of risk and addressing of risk in a culturally appropriate manner	Awareness of risk and interest in handling risk in a culturally appropriate manner

4.4 OPPORTUNITIES TO IMPROVE SELF-MANAGEMENT SUPPORT IN SWEDEN

In comparison to Uganda and South Africa, what are the opportunities to enhance self-management support in Sweden based on the SMART2D self-management framework?

As part of paper IV, a trans-disciplinary self-management framework (hereafter referred to as SMART2D framework) was developed. The SMART2D framework combines a comprehensive set of elements which facilitate self-management. The framework and its elements can be described in terms of the individual and the individual’s proximal environment. The framework focuses strongly on the community and the health system and their respective actors as postulated by the ECCM and other system-based models such as Health System Theory. This is considered in the SMART2D framework as the individual’s proximal environment. In addition, the role of the individual has been enhanced and further strengthened by behavior change theories (SDT in particular) through the three groups of individual or intra-personal factors: mediating factors (such as learning, self-efficacy); self-management skills (such as decision making, problem solving); and self-management tasks (such as medical, lifestyle management). This was considered to be significant as the individual has a key role in self-management that requires substantial skills, knowledge and resources for which they require continuous interaction with their proximal environment. This model development was informed by literature evidence and contextual data from the target population in the three countries: Sweden, South Africa and Uganda.

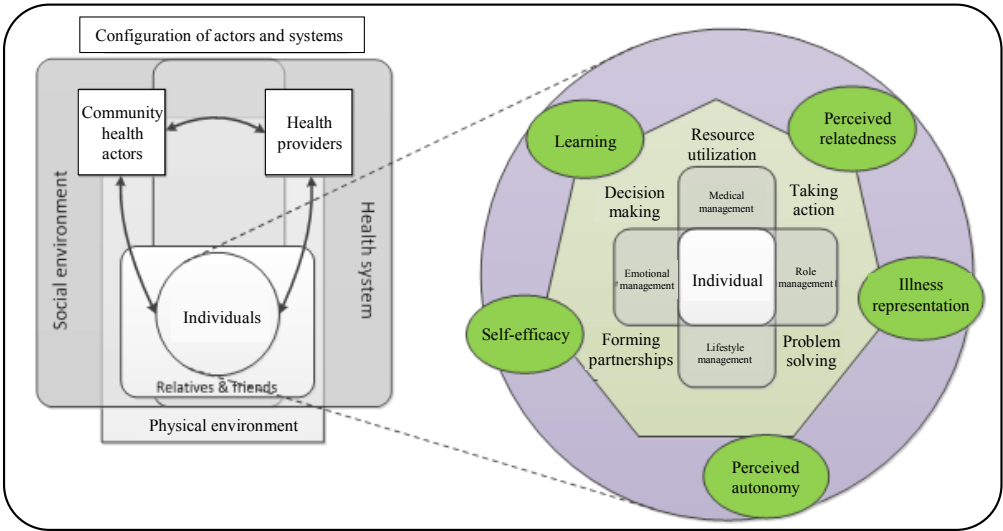


Figure 5: The SMART2D framework presenting the different elements that determine self-management.

Focusing further on the individual and the proximal environment elements of the SMART2D framework from the perspective of Sweden, both similarities and differences were identified in comparison to South Africa and Uganda.

At individual level firstly, persons with T2D/or at risk of T2D in Sweden and South Africa were highly mobile as both target populations were comprised predominantly of immigrants. The migrant population in South Africa was mainly represented by persons who had moved from other Southern African countries for work. High mobility was ascribed to people moving back to their home countries for long periods of time or relocating to other areas due to better employment. Mobility was seen to affect access and continuity of care at health centers particularly in Sweden where some patients, for example, were lost to follow-up.

Secondly, the individuals with T2D/or at risk of T2D in all sites were generally aware of T2D risk factors and self-management strategies but adherence to the lifestyle recommendations was experienced as a challenge in general. Socio-cultural views were attached to T2D risk factors particularly in Uganda and South Africa. Obesity for example, was seen as a sign of success. Additionally, religious and traditional beliefs influenced individuals' perceptions of T2D across the three sites. In Sweden however, T2D was not considered severe and dangerous as in Uganda and South Africa.

Thirdly, in Sweden as in Uganda and South Africa, family and friends were reportedly useful in providing psychological support and help with practical self-management tasks to patients including preparation of healthy meals, and reminders to conduct physical activity.

At the level of the individual's proximal environment, firstly, interactions between patients and providers in Sweden seldom went beyond the formal patient-provider interactions during clinic visits. In contrast, in Uganda and South Africa, providers referred and linked patients to treatment supporters in the communities. These included health clubs with peer-led or professional-led self-management and health promotion education. In Sweden on the other hand, only limited formal interactions were observed between communities, local and regional stakeholders in health promotion and prevention activities and this was also true for T2D prevention and management.

Secondly, although self-management is an established care strategy for patients with T2D and pre-diabetes in Swedish PHC centers, support for self-management was limited. The providers were not adequately equipped to tackle the different cultural and social needs of

their patients. In Uganda and South Africa, traditional and poorly trained providers risked misinforming their patients.

Thirdly, the structure of T2D care is more established in Sweden compared to Uganda and South Africa. This involves integrated primary care comprising multidisciplinary teams of health professionals, referral systems and electronic medical records. The challenge in Sweden is the long waiting times and lack of support between the follow-up visits. In South Africa, essential T2D care exists and similar challenges were observed. In Uganda, several challenges including lack of supplies, unqualified staff, and lack of T2D care guidelines were found to hamper the quality of care.

Fourthly, in Sweden available resources within the local community were not optimally capitalized upon. While sporting activities are well accepted in the general community, this was not the case in the target population where poor weather conditions and a perceived lack of safety were often cited as barriers to this type of physical activity. In the other two settings, sports was not commonly accepted as a way to improve health.

5 DISCUSSION

This PhD project focuses attention on a few key aspects of T2D prevention and management in Swedish primary care, namely the mismatch in expectations between patients and providers with respect to self-management; the lack of recognition of pre-diabetes as a high-risk state for which significant preventive action is possible; and the undefined role of the community and challenges thereof in the provision of self-management support. These aspects are discussed below in the light of the conceptual framework (Figure 1).

Mismatches in the expectations of self-management between patients and providers

Participants in the present research studies did not perceive T2D diagnosis as serious compared to other chronic conditions such as hypertension. Earlier studies conducted among similar populations have shown patients of non-European background to not perceive diabetes as serious and attribute the disease to fate or supernatural factors such as God or Allah [42, 114]. Such views have been shown to have consequences on patients' uptake of lifestyle advice [115], often causing frustration for providers.

One of the key findings from these research studies is that patients and providers experienced different dilemmas associated with the implementation of self-management practices and acceptance of lifestyle advice. As patients struggled to adjust their daily routines to accommodate the recommended lifestyle changes, the providers felt inadequately equipped to manage the diverse social and cultural needs of the patients. Our findings concur with findings from other studies which demonstrate challenges in the implementation of self-management from patients and providers' perspective [116-119]. The findings further suggest a disconnect between patients and providers in tackling self-management. As demonstrated in the present studies, lack of cultural awareness among providers has previously been shown to result in general practitioners ignoring cultural differences during meetings with immigrant patients [70]. Moreover, providers have been seen to face a dilemma with respect to patients' role in self-management. They expect the patient to take the lead in the management of their diseases, but also believe that patients are incapable of doing so, which results in providers having to intervene [120]. Such thoughts from providers may contribute to limited efforts by providers to control their diabetes. Self-management represents a shift towards a person-centered approach to chronic disease management, which emphasizes partnership between providers and patients

in order to support patients achieve their health goals [116]. As suggested in the ECCM, supporting patients to self-manage includes but is not limited to provision of traditional health education messages such as those focused on tobacco use, nutrition and physical activity [69], but also build patients' personal skills to exercise control over their health and environment [69]. Thus disconnect in patient and providers' experiences of self-management suggests barriers in the patient-provider collaboration which might consequently uptake affect uptake of self-management advice.

Pre-diabetes as a high-risk state of type 2 diabetes

Participants had overall awareness of diabetes and the possibility of developing T2D but pre-diabetes was not recognized as a diagnosis and persons at risk were uncertain of its significance to everyday life. Previous studies have shown that increased patient awareness of pre-diabetes is associated with increased engagement in lifestyle modification [33, 39, 40, 121, 122]. Increasing patients' awareness of pre-diabetes could result in elevated performance of physical activity and weight management behaviors and in turn reduced risk of future diabetes [121]. Despite the awareness of increased risk of diabetes most participants with pre-diabetes did not recognize the immediate need to engage in lifestyle modification activities. A possible explanation could be that people with pre-diabetes do not understand their condition well enough to act upon it. This is in line with the ongoing debate as to whether pre-diabetes is a useful diagnosis, considering the differing diagnostic criteria being used around the world [4] .

Additionally, the use of the term pre-diabetes to describe T2D risk brings with it uncertainties pertaining to its meaning and relevance to everyday life, observed in the present study and also reported in previous studies [35, 36]. Moreover, healthcare providers' views with regards to the application of the term pre-diabetes in communicating risk have been found to vary [38, 39]. Some healthcare providers reported that the term was useful as an incentive for behavior change among some persons with pre-diabetes [39] while others saw no benefit in the application if the term while communicating T2D risk to their patients [38]. Such uncertainties and inconsistencies in the meaning and use of the term pre-diabetes calls for further research to better understand the relevance of pre-diabetes as a term to communicate increased risk of T2D. Additionally, sensitizing people and health actors about the risk of T2D, the benefits of early diagnosis is the start point for health promotion and T2D prevention.

Role of community

Understanding the context of community is critical in design and contextualization of self-management support interventions as well as engagement of communities in health promotion and disease prevention. In one of the present studies, community was defined by geographical location and socioeconomic status i.e., living in close proximity and sharing limited resources. The meaning of community in our study setting surpassed boundaries of age, nationality and ethnicity. Similar findings have been seen in a recent study conducted in a similar setting in Sweden [123] and previous studies from several other countries [57, 58, 60]. Parallel to Hamed et al's findings on perceptions of community [123], the feeling of community came from living in a socioeconomically disadvantaged neighborhood, distinct from other areas in the Stockholm region. Such feelings have created a sense of isolation among the community members, which is further demonstrated in the consistent use of the 'us and them' when comparing their neighborhood to others. Irrespective of diversity, living in a socioeconomically disadvantaged neighborhood is a commonality among the community members a key consideration when contextualizing interventions.

Earlier studies have demonstrated that engaging the community in health promotion and disease prevention programs has great potential in enabling people to increase control over their health and encourage healthy choices [124, 125]. However, the present research studies, the interaction between community stakeholders was limited as was engagement in T2D prevention. In comparison to South Africa and Uganda, community ties to the Swedish health system were found to be loose and community initiatives for self-management support were less prominent. A possible explanation could be that the health system is oriented to clinical and hospital based care with limited efforts towards prevention [89]. Additionally, despite the availability of resources for physical activity, these are not capitalized upon. In order to provide equitable and person-centered care to all citizens migrants inclusive, there is a need to build effective bridges between the healthcare workforce and communities, involving outreach or community care liaisons to strengthen social cohesion and decision-making among migrants. Barr et al [69] also emphasizes that efforts for promoting effective health promotion and prevention should go beyond establishing linkages with community resources relevant to chronic illness care but, allow the community to take lead in addressing its needs and developing strategies to meet those needs [69]. Thus, support for self-management in coping with T2D should be holistic involving providing health information, enhancing personal skills for health and wellness of the individuals and engaging communities in the management of their own health.

Another key finding from the present research studies was that all the stakeholders showed awareness of the burden and risk of T2D in their communities and interest in tackling it in culturally appropriate ways, community diversity was raised as a major barrier. From an implementation and health systems perspective, it is challenging to deal with diversity in multicultural settings [126]. Mobilization of support and interest for health actions and to meet the needs of diverse populations while ensuring equality [123] is particularly difficult. An intercultural approach could be an appropriate means to address diversity in the implementation of prevention interventions in such settings [127-129] as it accommodates population differences, yet focuses on the common characteristics of the target group [127]. In the case of the present research study, the participants' perception of community was based on commonality of living in socioeconomically disadvantaged communities with limited focus on their differences. Although inter-culturalism has not been widely explored in global health research, it may offer a pragmatic solution to addressing diversity during contextualization and adaptation of health services and interventions, particularly in cities within Europe where geographically clustered complex heterogeneity is becoming a common feature today [130].

In summary, the findings from the PhD studies contribute to the arena for action in this expanded notion of self-management in the ECCM, through highlighting the key actors in self-management support and the gaps and opportunities in the self-management process that should be considered in the design and implementation of support strategies in the community as well as in the health system.

5.1 METHODOLOGICAL CONSIDERATIONS

The sample sizes in studies I, II and III were deemed sufficient to answer the research questions in the studies based on Malterud's description of information power [131]. In all the studies, the research questions were relatively specific and these informed the selection of study samples. Additionally this thesis was informed by theory through application of the conceptual framework.

The key argument for the use of qualitative research methods in the PhD project was the opportunity they lend to considering context [132]. At the same time, contextualization is also a limitation in terms of transferability of the findings. Super diversity in Sweden goes beyond ethnic diversity [133]. It draws attention to complex interlinking variables (including socioeconomic status, country of origin, language, age, sex and education level)

that differentiate people's rights and privileges as migrants, citizens, and workers in novel ways [133]. Little has been studied in regard to diversity [133] in Sweden yet it makes transferability a challenge. To adapt to this situation, selection of the study sample was based on geographical location (socioeconomically disadvantaged suburbs) and migration status, which are common characteristics of the population in the suburbs of Sweden. In this way, the views and experiences of different groups of people within the population are represented in the sample selected. For the same reason, the findings of this project are arguably transferrable to other socioeconomically disadvantaged settings in high income countries with a high proportion of immigrants and a similar health system funded by the government.

A detailed description of the data collection process and transparency regarding the analytical procedures address considerations pertaining to dependability as described by Lincoln & Guba, 1995. To enhance credibility of the project studies, triangulation [104] was conducted in terms of data sources (including patients, healthcare providers, community stakeholders), data collection methods (observations, individual and group interviews) and investigators, allowing for comparison of different perspectives. Credibility and dependability was further enhanced through the PhD student's engagement in data collection, interaction with the study participants via *member checks* (Lincon & Guba) and *peer- debriefing* [93, 94, 104]. Peer-debriefing, is a technique where a researcher presents the preliminary findings to his/her colleagues and receives feedback and input from those outside the research process [94]. The technique allowed the PhD student to evaluate herself in the research process.

5.2 REFLEXIVITY

Confirmability was assessed through my experience and role in the research process [94]. My involvement in the larger SMART2D project provided a solid understanding of the context in which the studies were conducted, hands on experience was gained through participation in the design of the studies, development of the data collection tools and data collection process. This level of project involvement brought with it some challenges, as it was at times difficult to disentangle the processes of research and implementation processes of the trial. This however was resolved through supervision meetings and streamlining of PhD student roles and other assigned project roles.

Being a nutritionist and a public health specialist who has worked with undernutrition at community level in a low- income country setting (Uganda) for several years prior to the doctoral studies prepared me for field work. Although the contexts were different, interaction with the community stakeholders, patients and healthcare providers came naturally. This was further enhanced by my multi-lingual abilities including the ability to speak Swedish. My background inspired my interest in the research area and also influenced the framing of the research questions addressed in this project. Familiarity with the study context and research concepts was an adaptive learning process, like peeling several layers of an onion and learning new things about the community and health system together with its processes.

Mobilization and recruitment of study participants was a challenge. My experiences as foreign-born student who has lived in a similar suburb as the study settings was advantageous for me during the research process as role oscillated between the insider (the migrant) and outsider (the researcher) [104]. Working with a multi-disciplinary research team also brought in a blend of perspectives during the data analysis [94, 104].

The application of a common conceptual framework and the framework method in study IV facilitated cross-learning among the three different sites. Active involvement of the local research teams in the translation of the framework to the data collection guide promoted contextualization. The framework was comprehensive and yielded rich data on the determinants of self- management in the respective contexts. However, this process was challenging and resource intensive. The process required several online meetings and workshops with the implementation teams from the respective study sites. It also required a focus on certain elements at the cost of others, based on what the teams estimated as relevant for their context and what was feasible in terms of data collection. Application of the framework for data collection was equally challenging for the implementation teams. They perceived the topic guide as very broad, theory-driven, and difficult to adapt to the local contexts. Abstract concepts such as the psychological mediators (e.g. perceived autonomy, self-efficacy) were difficult to translate and measure, which could explain why data related to some of these theoretical constructs is sparse for all study sites. The self-management framework was developed based on literature reviews and expert consultations, and applied in study IV to inform data collection, analysis and interpretation. However, for assessment of the internal validity and interconnections between different elements, quantitative research is needed.

6 IMPLICATIONS FOR RESEARCH, POLICY AND PRACTICE

The findings of this thesis highlight mismatches in the patients' and providers' perceptions and experiences of self-management, which translate to barriers in the delivery of lifestyle advice for persons with T2D and pre-diabetes. There is a need to build the capacity of health care providers within primary care to provide culturally and socially tailored advice, particularly for pre-diabetes. The current Swedish diabetes care guidelines lack specific strategies and guidance on provision of culturally appropriate lifestyle advice. Focus on persons at risk of T2D would be an essential part of an integrated prevention strategy.

The limited linkages between communities and other stakeholders at local and regional level in health promotion and prevention activities signifies the narrow scope of actions and actors engaged in self-management support for non-communicable diseases such as T2D. The chronic care model and others have already established the need to go beyond facility-based care for these diseases. Lessons can be learned from Uganda and South Africa where engaging communities in the management of their own health has proven effective in shifting tasks such as prevention from the formal health system to the community and reducing costs to the system.

Heterogeneity in ethnicity and nationality within smaller geographic areas translates to diversity in expectations with respect to prevention and management services. This re-emphasizes the need for personalized and tailored preventive strategies that focus on socioeconomically disadvantaged groups. Intercultural approaches focused on the commonalities within the communities rather than the differences could be a means to address these needs.

The findings from this thesis have contributed to the process of strengthening self-management support for diabetes and pre-diabetes in socioeconomically disadvantaged areas in Stockholm, Sweden with a high proportion of immigrants. More precisely, the studies have informed the design of a feasibility trial testing the effectiveness of telephone-based lifestyle coaching for participants with T2D and high risk, with the involvement of peers or care companions if desired. The studies highlight the importance of formative research in lifting contextually different realities when developing and implementing interventions for chronic disease prevention and management.

7 CONCLUSIONS

Self-management entails complex processes, actions and actors. Patients and providers experienced dilemmas pertaining to self-management in practice. As patients struggled to integrate self-management into their daily routines, providers were inadequately equipped to handle the diverse social and cultural needs of their patients (Study I). Pre-diabetes was not recognized as a diagnosis and persons at risk were uncertain of its significance in everyday life (Study II). Community members perceived community as living in close proximity and sharing the same resources. There was limited formal interaction between communities and local and regional stakeholders in T2D prevention and management (Study III). The Swedish primary care system has established routines for the management of T2D, but support for self-management is more focused on the ‘why’ rather than the ‘how’. Based on lessons from South Africa and Uganda, formalizing ties between communities and primary care has the potential to significantly improve self-management support for T2D among Socioeconomically disadvantaged communities in Sweden (Study IV). Strengthening local and global collaborations is one major step in reducing T2D burden and thereby contributing to the sustainable development goals and Agenda 2030.

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10 APPENDICES

10.1 APPENDIX 1

Semi-structured interview guide for people with type 2 diabetes

Theme 1: Perceptions of type 2 diabetes diagnosis

1. Please describe the period just before you got the T2D diagnosis: how did you feel?
2. Tell us about the consultation when you received your diagnosis?
3. After you had been diagnosed, how did you react?
4. If you were to compare the reactions you got when you received diabetes diagnosis do you think that they would be the same as if you got a diagnosis of another chronic disease?
5. If you were to compare the reactions you got when you received the diabetes diagnosis with the reactions you have noticed that other people with diabetes got, do you think that these reactions are similar? What about people with high blood pressure – what reactions do they get? What about people with other chronic diseases?

Theme 2: Diabetes care, patient and provider interactions

1. Can you describe your contact with the healthcare center?
2. During your visits to the health center what do you talk about?
3. Please describe the information you receive during consultations at the healthcare center
4. What changes have you made in relation to your diet, smoking, physical activity after your diagnosis?

Theme 3: Experiences of diabetes self-management

1. Can you describe what you do on a daily basis to manage your condition?
2. Please describe how you feel and what you do to keep your blood sugar stable on a good day?

Theme 4: Support for self-management

1. If you think about your everyday life with diabetes – describe the support you have received?
2. What challenges have you faced during the management of your condition?

10.2 APPENDIX 2:

Semi-structured interview guide for people with persons at risk of diabetes (Pre-diabetes)

Theme 1: Perceptions of risk for diabetes

1. Please describe the period just before you got to know that you were at risk of diabetes
2. Tell us about the consultation when you received your diagnosis?
3. After you had been diagnosed, how did you react?
4. If you were to compare the reactions you got when you received pre-diabetes diagnosis do you think that they would be the same as if you got a diagnosis of diabetes or another chronic disease?
5. If you were to compare the reactions you got when you received the diagnosis with the reactions you have noticed that people with diabetes got, do you think that these reactions are similar? What about people with high blood pressure – what reactions do they get? What about people with other chronic diseases?

Theme 2: Care for persons at risk of diabetes and interaction with healthcare providers

1. Can you describe your contact with the healthcare center?
2. During your visits to the health center what do you talk about?
3. Please describe the information you receive during consultations at the healthcare center
4. What changes have you made in relation to your diet and physical activity after your diagnosis?

Theme 3: Experiences of coping with the risk of diabetes

1. Can you describe what you do on a daily basis to manage your condition?
2. Please describe how you feel and what you do to keep your blood sugar stable on a good day?

Theme 4: Support for persons at risk of diabetes

1. If you think about your everyday life as being at risk of T2D– describe the support you have received?
2. What challenges have you faced during the management of your condition?

10.3 APPENDIX 3

Semi-structured interview guide for healthcare professionals and health managers

Theme 1: Diabetes care, patient and provider interactions

1. How is diabetes care organized at this healthcare center?
2. Describe the typical patient seeking diabetes care here?
3. How do patients react when diagnosed with T2D?
4. Please describe the type of treatment programs you offer newly diagnosed patients?
5. How do patients react to becoming diagnosed with diabetes?
6. How do you describe self- management to the patients? How do they understand it?

Theme 2: Caregiver's experiences and support for self-management

1. Do you offer other types of support to the T2D patients?
2. What challenges do you encounter in the treatment of patients with diabetes as compared to patients with other lifestyle-related diseases?
3. How do you view the need for diabetes prevention and primary health care treatment in areas with a large proportion of migrants in relation to areas where most people are born in Sweden?
4. Perceptions of disease causes can vary between different cultures and it can be difficult for the doctor and the patient to understand each other- Do you think this is a problem in diabetes care here?
5. To what extent do you think that proper care and support are offered to diabetes patients?
6. If a patient has trouble following treatment and recommendations, how is that managed?

10.4 APPENDIX 4

Semi-structured interview guide for local network leaders/community members

Theme 1: Perceptions of community

1. Community can mean different things for different cultures - How do you understand the term community?
2. What networks are found within this community?
3. How do people become members in these networks?
4. How are activities coordinated?
5. Language is seen to be an important means to communicate – In what way does language affect people's participation in the proposed networking activities in your area?

Theme 2: Perceptions of health and care

6. What does it mean for you to "feel healthy"?
7. What is your experience seeking care at the primary health care center?
8. If you think about the people you know - how do they choose which healthcare center they use?
9. What would you like to see changed in health care?

Theme 3: Support for persons with diabetes within the community

10. Have you heard of type 2 diabetes before this study?
11. What types of food do people in your network usually eat?
12. What are the common physical activities most people do in your local area?
13. What do you think people in the community are doing to prevent diabetes?
14. In terms of diabetes prevention, what is the role of the network?
15. What do you suggest that society in general can do to improve the community's eating habits and physical activity?
16. If you had a diabetic patient today, how would you support them to ensure that they follow their treatment plan from the healthcare center?
17. How do you expect the rest of society to support you in taking care of this patient?

10.5 APPENDIX 5

Semi-structured interview guide with health actors at national and regional institutions

Introductory questions

1. What is the mission your organization?
2. What is your role in the organization?

Theme 1: Experiences of interacting with the local community

3. What activities is your organization engaged in with in the community?
4. How does your organization interact with community networks?

Theme 2: Awareness of diabetes burden in the community

5. What have you heard being said about diabetes in the community?
6. How do people with diabetes in the community manage the disease?

Theme 3: Health promotion and diabetes prevention

7. How is your organization working round the communities to promote health?
8. What programs is your organization involved in to prevent diabetes in the community?
9. How can your organization support community members with pre-diabetes and type 2 diabetes to make lifestyle changes?
10. Cooperation between various organizations in society- How do you think you to cooperation can be established between organizations for to support to lifestyle changes so as to prevent diabetes?
11. What challenges do you face in your work with the community?
12. What strategies would you recommend for local and regional authorities to interact and engage with communities to prevent diabetes
13. Which Other actors do you think would be relevant in development of these strategies.



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